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MENTAL RETARDATION--THE PRESENT PROBLEM.

BY- SHAFTER, ALBERT J.
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MENTAL RETARDATION IS DEFINED AS A MENTAL DEFECT, NOT A DISEASE. LEVELS OF SEVERITY IN MENTAL RETARDATION ARE CAUSED BY AN INTERRELATIONSHIP BETWEEN HEREDITY AND ENVIRONMENT. ONE OF THE MAJOR PROBLEMS CONCERNS THE LONGER LIFE EXPECTANCY OF THE RETARDATE DUE TO IMPROVEMENTS IN MODERN MEDICINE. THIS IS CREATING A SITUATION WHERE RESIDENTIAL FACILITIES DO NOT HAVE THE SPACE TO CARE FOR NEW ADMISSIONS. SUCH FACTORS AS MOBILITY, LACK OF EDUCATIONAL OPPORTUNITIES, DANGER, AND ECONOMIC USEFULNESS ARE INTERACTING TO CHANGE THE RURAL ATTITUDE AGAINST INSTITUTIONALIZATION. THE ARTICLE CONCLUDES THAT TRANSPORTATION AND PROGRAM COORDINATION PROBLEMS WILL NEED TO BE SOLVED IN ORDER TO ESTABLISH ADDITIONAL FACILITIES IN RURAL AREAS. THIS PAPER WAS PREPARED FOR PRESENTATION AT THE NATIONAL CONFERENCE ON PROBLEMS OF RURAL YOUTH IN A CHANGING ENVIRONMENT (SEPTEMBER 1963). (JS)

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by

Albert J. Shafter, Ph. D.
Superintendent
Enid State School
Enid, Oklahoma

National Committee for Children and Youth
1145 Nineteenth Street, N. W.
Washington, D. C. 20036

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Albert J. Shafter, Ph. D.
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in a Changing Environment

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ABSTRACT

The problem of mental retardation in rural areas is a vast unknown. Retardation has become a national concern only in the past few years, but much confusion still exists concerning this subject.

Today there is agreement that the mentally retarded may be classified into four major categories: profoundly retarded, severely retarded, moderately retarded, and the mildly retarded. Moreover, a fifth category, those of borderline intelligence, is of equal concern.

The numbers of mentally retarded varies by surveys, but it is estimated that approximately two to three per cent of the population is mentally retarded. More significant than gross numbers, however, is the fact that the mentally retarded are living longer than ever before.

The attitudes of rural families toward the mentally retarded child appear to be changing. In increasing numbers rural families are institutionalizing their children. On the other hand, other rural families prefer to keep their child at home but demand local facilities to assist in his care.

Local facilities for rural families are virtually non-existent. Problems of transportation for dispersed population and coordination of activities must be solved before effective programs can be established.

DEFINITION AND TERMINOLOGY

While considerable progress has been made in accenting mental retardation, some confusion still remains over what is really meant by mental retardation. In large part this may be due to changes in the meaning of terms among the professionals. Thus, today rather than speaking of the mongoloid (an acceptable term less than two years ago), this syndrome is now called Downs' Syndrome after Downs, the person who first called the condition Mongolism.

Clarification of the confusion regarding terminology and definitions related to mental retardation is an obvious and necessary starting point. First, what are the differences between the feebleminded, mental deficient, and mentally retarded? For all practical purposes there are none. In earlier days some persons were called feebleminded, but it was decided this had a bad connotation. Mental retardation and mental deficiency then were both used, and while an attempt was made to differentiate the two terms, they are now used interchangeably. 1/ Today, mental retardation is used most often.

Given this, the real question is what does it mean when an individual is said to be mentally retarded. It does not mean the individual is mentally ill, although the mentally retarded can become mentally ill, recover from their illness and still remain mentally retarded. The American Association on Mental Deficiency defines retardation as " . . . mental defect existing from birth or from an early age, (persons who) are incapable of profiting from ordinary schooling and/or incapable of managing themselves and their affairs with ordinary prudence." 2/ Thus, mental retardation is not a single entity or disease but rather a condition of subnormal mental development which exists either at birth or early childhood. 3/

French has pointed to the dangers of over simplification of the concept of retardation and reliance on the intelligence quotient as a measure of retardation. 4/ However, for our purposes, psychometric examinations plus medical, social, and education evaluation will place the mentally retarded in one of four large classifications. Here again, problems of change in terminology arise.

Originally, the most retarded individuals were called idiots. These are individuals who cannot protect themselves from common physical dangers. They may have no depth perception and walk off a large height, burn themselves, etc. At best they may learn a few simple words but even here, their usage may be incorrect. Later, it was decided that idiot was a bad term and they were called low grades which was rejected rather quickly. After briefly flirting with custodial or permanent care, this category was named profoundly retarded.

The imbecile, the individual who will need either institutional or close family supervision, suffered a similar fate. After passing through the middle grade stage and the educator's trainable classification, this

category was split. The most involved who could walk and do a few extremely simple activities are called severely retarded. Those who can avoid common dangers, carry on a simple conversation, but who must have close supervision to carry on the affairs of every day living whether at home or in a residential facility, are moderately retarded.

The moron, high grade, educable and now mildly retarded individual can in most cases with proper training, be a self-supporting individual. It is a fact that very few ever come to residential facilities. Certainly every one of us meet these people each day. It is a commentary on our problems that such persons are frequently not "retarded" until they are defined as such. If they do not come to the attention of a welfare agency or police department, they may live out their lives without being called or regarded as mentally retarded. Generally, this type of retardation is associated with the lower socioeconomic groups.

Finally, there is a fifth interstitial group, those of borderline intelligence who are between the mildly retarded and the dull normal. The great majority of these persons are capable of independent living.

It should be noted that the profoundly and severely retarded generally have more physical deformities than the moderately and mildly retarded. This, of course, means additional problems in planning programs for these people. Table I summarizes the changes which have occurred in thinking regarding the classification of mental retardation.

TABLE 1.

CHANGES IN TERMINOLOGY AND I.Q. IN MENTAL RETARDATION

TERMINOLOGY	I. Q. RANGE
Idiot - Low Grade	Less than 20
Profoundly Retarded	Less than 20
Imbecile - Middle Grade - Trainable	20 - 49
Severely Retarded	20 - 35
Moderately Retarded	36 - 51
Moron - High Grade - Educable	50 - 69
Mildly Retarded	62 - 67
Borderline	68 - 83

CAUSES OF RETARDATION

As noted above, mental retardation is a condition which describes individuals ranging from those who are completely helpless to those who are capable of independent living. It is obvious then that there are many different causes of retardation; moreover, there is relatively little agreement concerning causal classification. It has been estimated that there are

hundreds of separate causes of retardation. One of the most comprehensive reviews of the literature may be found in Clarke and Clarke. 5/

While terminology and theories vary greatly, there appears to be agreement that the causes of retardation may be classified either as an alien or new character of a pathological nature not normally found or those who are "normal" variants from the population and who, through heredity or poor environment, are retarded. Again, it should be noted there are many variations of these basic concepts. Parenthetically, both heredity and environment may play a part in either classification.

Pathological defects have been classified in five ways by Clarke:

1. Rare dominant defects, e.g., Huntington's Chorea
2. Rare recessive defects, e.g., Phenylketonuria
3. Rare sex-linked defects
4. Environmental factors
   a. Blastophthonia (germ plasm injuries), x-ray, lead poisoning, etc.
   b. Prenatal influences on the fetus, e.g., measles
   c. Natal factors; birth injuries
   d. Postnatal influences, e.g., meningitis
5. Defects of obscure origin, e.g., mongolism 6/

Many other examples could be given but this list illustrates the point that two healthy parents may, because of recessive or dominant gene defects, because of injury to the germ plasm, the fetus, at birth or shortly thereafter, have a mentally retarded child.

There is no discernible organic cause for the great majority of persons who are classified as mentally retarded. Unless one is prepared to accept the either/or proposition that mental retardation is a function of heredity (retarded parents have retarded children) or environment (living conditions create retardation) explanations grow quite complex. 7/ The present state of knowledge suggests there is an interrelationship between heredity and environment, particularly in the etiology of the mildly retarded individual. The difficulty comes in weighing the relative importance of each factor.

PREVALENCE AND INCIDENCE

It is somewhat disconcerting to find one of the nation's major health problems has never been completely identified as to its scope. It is comforting to rely on the estimate of the World Health Organization that two per cent of the population is mentally retarded or the three per cent estimate of the National Association for Mentally Retarded Children. Nevertheless, many pamphlets still use Penrose's findings that the "feeble-minded" (moron or mildly retarded) include 2.26 per cent of the population, the imbeciles 0.24 per cent and the idiot 0.06 per cent with an implication of complete precision. 8/

The fact remains, however, that a number of surveys have been made which yield a variety of figures for the incidence and prevalence of mental retardation. (The terms are used here in the sense O'Conner described: incidence is the number born each year while prevalence is the total number of disorders existing in a defined population). 9/ Moreover, the majority of the surveys are concerned with the urban or metropolitan areas. It is truly unfortunate that we know so little about the problems of mental retardation in rural areas of the United States.

Two excellent analyses of the problems related to defining incidence and prevalence have appeared. O'Conner notes three major difficulties in measuring the extent of the problem. They are (1) lack of precise criteria; (2) unreliability of the instruments of measurement; and (3) historical, social, and personal variation which alter the liklihood of classifying individuals as retarded. 10/ The first two points are self-explanatory. The third again points up the fact that surveys are done by individuals for a particular purpose; since these vary, their findings will vary also.

Gruenberg strikes a more controversial point for consideration when he suggests the 2.0 to 2.2 per cent estimate of retardation may be a function of certain statistical assumptions of the test constructors which may have no basis in reality. 11/ This, of course, neither affirms nor denies the fact that estimation may be either high or low.

In general, however, most surveys of the problems seem to agree that the prevalence of mental retardation is approximately twice as high for males as females. Second, age fourteen seems to be the age category which holds the greatest number of mentally retarded. Third, there is little or no evidence to support either the contention that the proportion of the retarded is decreasing or increasing in the population. Fourth, there is no evidence to support the assumption that mental retardation occurs proportionately more frequently in either rural or urban areas. This last point will be discussed in detail later.

Gruenberg offers three alternative hypotheses as to why males outrank females in frequency of retardation. They are: (1) males are more susceptible to the extrinsic factors or agents which produce retardation, (2) standards for intellectual development are related to communication skills which are more readily learned by females; or (3) damaged females die more frequently than damaged males. 12/ Another consideration is that parents may be more willing to institutionalize a boy than a girl. Gruenberg also suggests the reason age fourteen is the high mark for retardation is because older persons lose their identification as mentally retarded and slip back into the "normal" population.

Epidemiological surveys and administration of programs are now being confronted with a new problem since modern medicine has disrupted actuarial predictions of life expectancy for the profoundly, severely, and moderately retarded. Perhaps the best example is the mongoloid who less than twenty years ago was said to have a life expectancy of nine to fourteen years. Mongoloids are highly susceptible to upper respiratory infections and early

deaths commonly occurred because of pneumonia. Antibiotics, however, have drastically decreased this cause of death. Actually, at this point, it is not possible to forecast life expectancy for the mongoloid. Some suggest that a heart malfunction or an increase in chemical unbalances creating acidity may cause death around age forty. This, of course, is speculation but it is known that the mongoloid is living longer than previously. Newer medical advances may prolong life to a point where these individuals will live longer, on the average, than the normal population.

In the final analysis, the fact that the mentally retarded are living longer has far more significance than whether they compose one, three or even five per cent of the population. Fifteen to 20 years ago residential facilities for the mentally retarded had no waiting lists. Today, in most states, children may be found who have been waiting four to six years for admission. Within their families and communities, children and adults now sit doing nothing, a burden and drain on their families. Lack of facilities has prevented these persons from achieving even the minimum they are capable of, let alone the maximum. A few years ago they would not have been alive. Yet, our programs today are still based on the fallacious assumption of a high and early mortality rate for the moderately, severely, and profoundly retarded.

CHANGING RURAL ATTITUDES TOWARD MENTAL RETARDATION

For a number of years there has been a rather pleasant assumption that mental retardation was an urban problem. The "proof" was the fact that urban areas contributed disproportionately large numbers of first admissions to residential facilities. An investigation in Iowa in 1920 indicated the proportion of first admissions was roughly the reverse of the split in the rural-urban population; whereas Iowa in 1920 was approximately 80 per cent rural, approximately 80 per cent of the first admissions were from urban areas. In 1940 44.6 per cent of Iowa was urban, but Shafter and Coe found that 68.9 per cent of all first admissions came from these areas. 13/

In a more intensive analysis of Iowa and New York for 1940 and 1950, Shafter and Kenkel found that while urban areas continued to contribute a disproportionate share of first admissions to residential facilities for the mentally retarded, the number was decreasing significantly. 14/ An examination of first admissions for 1960 for these two states reveals that the trend has continued. It would appear that by 1970 or 1980, first admissions will be approximately proportionately equal for rural and urban areas. Therefore, the "proof" no longer has validity.

The significant increases in numbers of first admissions from rural areas led Chandler and the writer to begin an investigation to determine why rural families had decided to apply for institutionalization of their child. 15/ Unfortunately, before the study was completed, the investigators left Iowa. Therefore, the findings presented here are suggestive rather than definitive.

Briefly, 35 rural families who had applied for institutionalization of their child were interviewed. All children had been classified either profoundly, severely or moderately retarded. Interviews were open-ended, lasted several hours, and revolved around the question of what had been the determining factors in their decision to apply for institutionalization of their child. It became clear that five sets of factors, often interdependent, seemed to be operating. No attempt is made here to place them in their order of importance.

First, farm housing is changing; the three-bedroom ranch dwelling throws the family in contact with each other to a greater extent than ever before. There no longer is the upstairs room to hide the "different" member of the family.

Second, increased mobility has decreased the isolation the farm family once experienced. The automobile brings visitors every day, and permits the farm family to go to town each day if they so desire. The retarded child can either be an embarrassment at home or a hinderance to the family's mobility. Moreover, some wives who wished to work in nearby villages and towns and, because of the mentally retarded child at home, could not do so.

Third, farming has become more complex and correspondingly more dangerous. Mechanization, mixing feeds, and the other demands placed upon the farm worker have gone beyond the capabilities of the moderately mentally retarded. The inability of the mentally retarded child to be helpful around the farm, plus the dangers involved, make him a liability rather than an asset. In recent years, placement specialists have found it increasingly difficult to find farm employment for the mildly retarded.

Fourth, the development of diagnostic facilities has made farm families, and their neighbors, aware that they have a mentally retarded child. The "different" child now becomes a retarded child, once the label has been placed on him.

Fifth, consolidation of schools with better screening but without special education classes has eliminated the mentally retarded child from community educational facilities. It is ironical that one room school houses could and did accomodate the retarded child.

In the final analysis, however, it was the conclusion of the investigators that a basic change had occurred in the attitudes of farm families toward mental retardation. The older notion that the family cared for its own was being subjected to the same pressures urban families had experienced years ago. Mobility, lack of educational opportunities, danger, and economic usefulness all played a part in changing some rather fundamental values of the rural family. This, of course, has been complicated by greater life expectancy for the profoundly and severely retarded child.

In summary, it now appears as though several things are occurring simultaneously to rural families and their mentally retarded children. Rural families seem to be acquiring urbanized values toward their children which

will be reflected in a greater number of children being institutionalized. However, with increased knowledge of the causes of retardation, it may be anticipated that most of the rural families who will keep their children at home, will demand facilities to assist in their care. As sophistication regarding retardation rises, so will the demands for special classes, sheltered workshops, day care centers, etc. In the past, requests for facilities for the mentally retarded have come from urban areas. It may be expected that similar requests will now come from rural areas.

FACILITIES FOR THE MENTALLY RETARDED IN RURAL AREAS

A perusal of the literature reveals few facilities located in rural areas which are designed to serve the mentally retarded in a specific area. As Rothman has said, "The truly forgotten mentally retarded child is one who lives in a rural area." 16/ Facilities may be found in rural areas but they are designed to serve rather wide geographical areas rather than a localized rural one. For example, the well known Marbridge Ranch in Texas could be considered to have a rural locale but young men from all parts of the state are sent there for training. 17/

In urban areas throughout the nation may be found sheltered workshops, day care and rehabilitation centers, etc., for the mentally retarded. As yet, few facilities have been established for areas with a dispersed population. 18/

The mentally retarded in rural areas are taken to urban areas for diagnostic purposes but the distance often eliminates them from the opportunity of attending day care centers, sheltered workshops, etc. Once the diagnosis has been established, most facilities are closed to them.

Kolstoe has reported the establishment of a combined employment training and evaluation center as well as a sheltered workshop in a rural area. 19/ At one point an attempt was made to provide day services for mentally retarded persons in the surrounding area. However, problems of transportation and scheduling led to a modification of this approach so while some did commute, a dormitory type of living was established.

Shafter and Renzaglia examined the problem of establishing a sheltered workshop in an area of dispersed population in Illinois. 20/ Although this survey was concerned with all types of disabilities it was found that there was a great desire for some type of sheltered workshop for persons in rural areas. However, problems of transportation and coordination of activities created a situation which did not lend itself to an easy solution. Urban areas have a great advantage with public transportation. The Illinois report recommended that regional centers be established for the purpose of serving a dispersed population. Within the region, satellite or sub-regional centers could be established for actual operation while the regional center would provide coordination for a variety of operations. In such a situation, the regional center would provide diagnostic and evaluation services as well as coordinates all sub-regional activities.

Whether this approach or another is adopted, it is clear that the previous experiences of urban areas will provide only suggestions for the future development of facilities for the mentally retarded in rural areas. Some paths have been outlined. It is now up to the Nation to decide what it wants to do for the mentally retarded. 21/

FOOTNOTES

1. For example, the American Association on Mental Deficiency now publishes two journals, the American Journal on Mental Deficiency and Mental Retardation.

2. Title page, each American Journal on Mental Deficiency.

3. Tizard, J., "Introduction," In Clarke, Ann M., and Clarke, A.D.B. (eds.) Mental Deficiency: The Changing Outlook, Glencoe, Illinois: The Free Press, 1958, p. 4.

4. French, Edward L. "Identifying the Retarded Child and His problems." Devereux Schools Forum, December, 1962, pp 1-7.

5. Clarke, Ann M. "Some General Principles in the Aetiology of Mental Deficiency." In Clarke and Clarke, op. cit., pp. 122-153.

6. Ibid.

7. See Stern, Zena, and Susser, Mervyn. "The Social Distribution of Mental Retardation," American Journal on Mental Deficiency, May, 1963, 67 pp. 811-821, for a review and discussion of the problems.

8. Penrose, L. S. The Biology of Mental Defect, Rev. Ed., London: Sidgwick and Jackson, London, 1954, pp. 33.

9. O'Connor, N. "The Prevalence of Mental Defect." In Clarke and Clarke, op. cit., p. 23.

10. Ibid, pp. 25-32.

11. Gruenberg, Ernest M. "Epidemiology of Mental Subnormality," Research in Mental Retardation, Chicago: University of Chicago Press, In press.

12. Ibid.

13. Shafter, Albert J., and Coe, Rodney M. "Administration Planning and Population Forecasting." American Journal on Mental Deficiency, October, 1956, 61, pp. 337-340.

14. Shafter, Albert J., and Kenkel, William F. "The Predictive Value of the Concept Familism." Alpha Kappa Deltan, Spring, 1959, pp. 36-38.

15. Chandler, Charles S. Community Resources Coordinator, South Carolina State Hospital, Columbia, S. C. A personal communication from Dr. Chandler was most helpful in preparing this section.

16. Rothstein, Jerome H. Ed., Mental Retardation: Readings and Resources, New York: Holt, Rinehart and Winston, 1961, p. 481.

17. Peck, John R. Clearing in the Wilderness, Austin, Texas: The Hogg Foundation, pp. 46-48.

18. See Melcher, John W., and Blessing, Kenneth R. "Special Education for Rural Retarded Youth," In Rothstein, op. cit., pp. 511-517, for a description of the Wisconsin program.

19. Kolstoe, Oliver P. "The Employment Evaluation and Training Program." American Journal of Mental Deficiency, July, 1960, 65, pp. 17-31.

20. Shafter, Albert J. and Renzaglia, Guy A. A Survey and Recommendations for the Disabled of Southern Illinois, Area Services, Southern Illinois University, Carbondale, 1962.

21. The President's Panel on Mental Retardation, A Proposed Program for National Action to Combat Mental Retardation, Superintendant of Documents, U. S. Government Printing Office, Washington, D. C., October, 1962.